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ABSTRACT

Alzheimers Disease (AD), an incurable disability which afflicts older adults, can have devastating emotional consequences for the victim and the family. In an attempt to determine the effectiveness of multifamily psychoeducational support, group therapy (MFPSGT), 22 persons (13 families) from the Alzheimer's Disease and Related Disorders Association (ADRDA) participated in a pilot support group. Prior to group sessions, members participated in individual interviews and completed a questionnaire about AD and the Moos Family Environment Scale. An Activities of Daily Living (ADL) questionnaire and the Kahn Mental Status Exam were completed for the patient. Members subsequently participated in six group sessions, consisting of a 1-hour lecture, and four small group discussions led by a facilitator. The six session topics were: the aging process; biological changes and behavioral manifestations; behavior management; family communication patterns; emotional factors (grief); and community and nursing home supports. Post intervention, the participants evaluated the sessions and were readministered the psychological assessment instruments. An analysis of the results showed that, as expected, no significant changes occurred in the patients, although a slight increase in ADL functioning was reported. Relatives did become more independent after the intervention, recognizing and fulfilling their own needs in order to better serve the patient. Lectures identified as most helpful were: the aging process; biological aspects; family problems; and grief. The small groups were viewed as helpful in increasing coping and decision making skills. (BL)

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MULTI-FAMILY PSYCHOEDUCATIONAL SUPPORT GROUP THERAPY FOR FAMILIES WITH A MEMBER AFFLICTED WITH IRREVERSIBLE BRAIN SYNDROME (ALZHEIMER'S DISEASE): REPORT OF A PILOT STUDY[a]

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Irreversible organic brain syndrome, particularly Alzheimer's Disease (AD), is a feared spector as persons age. The disease, with its devastating emotional consequences for the victim and for the family, has no known cause and no known cure. Current estimates of the incidence of the disease vary from 600,000 to 1.2 million persons in the United States. Most are over 60 years of age, although earlier onset may occur. Since the numbers of older persons are projected to increase relative to the population as a whole, the incidence of the disease will inevitably increase.[1]

The role of the family in the care of elderly members has received increasing attention. It has been estimated that families provide 80 percent of the physical care and emotional support necessary for elderly relatives, at great economic, personal and physical cost.[2]

The Alzheimer's Disease and Related Disorders Association (ADRDA) has been formed to educate, support and enhance well-being for afflicted persons, their families, helping professionals and the community, as well as to promote research. Members of the Denver Metro Chapter have indicated a dire need for emotional and practical support for families experiencing isolation, burnout, depression and incidents of neglect or abuse.

With the burden of care for most AD patients resting squarely on family members, innovative therapeutic methods are indicated to meet the burgeoning and unmet needs effectively and economically. Multi-Family Psychoeducational Support Group Therapy (MFPSFT) is a method we devised and tested, based on a review of family, group and multi-family group therapy literature, which identifies these as viable alternatives to individual or single family interventions.

The School of Professional Psychology at the University of Denver, with the cooperation of the Bethesda Mental Health Center (MHC) and the Denver Metro Chapter of ADRDA, planned and conducted this pilot study to determine the effectiveness of MFPSGT in direct service contact, with both educative and support functions included. Families with an AD member can be educated about 1) the disease process, 2) ways they can assist the patient at home or in a long-term care facility, 3) family and personal behavioral and emotional reactions and 4) community supports. They can exchange experiences as well as receive support for the reactions which take their toll on the patient and all family members and the decisions which must be made as the patient deteriorates.

METHOD

The project staff met with the MHC geriatrics coordinator and staff of ADRDA to plan specifics of format, content and recruitment of families. We had previously selected or designed the pre post test instruments and chosen a format of six two-hour sessions on topics outlined below.

Families were recruited primarily from ADRDA members in the MHC catchment area. Twenty-two persons, members of 13 families, attended most of the sessions. Before the sessions began, members had individual interviews with project assistants and were administered a true-false questionnaire about Alzheimer's Disease[c] and the Moos Family Environment Scale.[3] An Activities of Daily Living (ADL)[4] questionnaire was filled out on each patient by family members and the Kahn Mental Status Exam[5] was completed by the family for the relative at home or by nursing home staff.

During the first hour of a session, the entire group met for a lecture and discussion. After a break, four smaller groups, each led by a graduate student project assistant, met to share ideas, concerns and emotional reactions. Two recorders monitored group process and content. Their observations and ideas helped us plan the following sessions.

The participants evaluated the six sessions. During individual post-treatment sessions the psychological assessment instruments were readministered and the participant's need for further assistance explored.

SESSION CONTENT

The salient points of each session are presented below. Those intending to utilize MFPSGT are encouraged to read further in references cited.

SESSION I—INTRODUCTIONS; THE AGING PROCESS: In this introductory session an overview of the project was given and goals and ways by which project personnel and participants might meet them were discussed. Each participant stated personal goals for the series which, not unexpectedly, fit with the planned format. We emphasized mutual information exchange and problem-solving since the families know far more about the day-to-day problems than do most professionals.

Lecture: People in general, health and even mental health professionals hold many myths and stereotypes about the elderly. Society equates aging with disease. Therefore, those older persons who have actual disease are often ignored, since early symptoms mirror the myth of "senility," which holds that all older persons are forgetful, rigid, unable to learn, dependent and useless. Fears of personal aging affect not only older people and their family members, but also service providers.

Family members are particularly affected since they believe they "should be able to handle" the deviant, "crazy" behaviors. They lose their previous social supports and they feel stigmatized by others as incapable and non-caring. It is important for families to understand the disease process and the personal distress caused by being with a person whom one knew well but currently doesn't recognize. It is important for family members to acknowledge personal needs and find ways to meet them. (This theme was reemphasized in later sessions.)

SESSION II—BIOLOGICAL CHANGES AND BEHAVIORAL MANIFESTATIONS: AD is a presenile and senile dementia characterized by general, slowly progressive and irreversible intellectual decline which results in the need for total care and culminates in death. The disease accounts for approximately 60% of Chronic Organic Brain Syndromes.

The neuropathology of the disease focuses on three major brain tissue changes. First, senile or neuritic plaques, which consist of rounded, enlarged, abnormal neuronal processes, develop deposits of a starch-like protein called amyloid. Second, nerve cells in the brain become thick and twisted and, thus, dysfunctional. This twisted tissue mass is called a neurofibrillary tangle. Third, brain cells atrophy and there is evidence that AD causes an actual decrease in the number of nerve cells and shrinkage of brain size.

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b) Mary deMendonca and Cathy Kindquist served as recorders during this project. Martin Dubin, Psy.D., geriatrics coordinator, Bethesda Mental Health Center, assisted with the planning as well as the material in Session II. Janice deTemple and Linda Binkley, ADRDA, gave invaluable assistance with suggestions and recruitment of participants.

c) Elie Axelroth compiled the questionnaire. Robert H. Cook, M.D., University of Colorado Health Sciences Center, was consulted about item content. We are indebted to him for his interest and expertise. Copies available upon request.

Pathologists, upon autopsy, look for the presence of neuritic plaques and neurofibrillary tangles to make a definitive diagnosis of AD. While EEG's, CAT scans and other tests are helpful, they often produce equivocal findings in the early stages of the disease and, therefore, a definitive diagnosis is difficult to obtain.

Frequently, the behavioral manifestations of AD are more apparent indicators of the disorder than are the actual physiological changes. It is important to note, however, that the specific physiological changes in the brain are the cause of the behavioral changes.

The earliest and most pathognomonic sign of AD is memory loss. The individual begins to experience difficulty in remembering recent events and has significant problems with new information. Long-term memory remains relatively intact, however. The individual may also demonstrate poor judgment and reasoning, making errors that are out of character. Anxiety, depression, restlessness and sleeping disorders are also common.

Later stages of the illness are characterized by increased difficulties in language and speech, disorientation, wandering and emotional instability. Lack of social understanding appears in indiscreet behavior and bursts of excitement along with overall apathy. Behaviors like aggressiveness, which previously had been kept in check by social awareness and judgment, frequently erupt with disagreeable intensity. Motor dysfunction is also evident with disordered gait, muscle rigidity, primitive reflex behavior and disorientation, especially at night. Visual and auditory hallucinations may occur. As the AD patient gradually becomes more and more debilitated, total care becomes necessary.

SESSION III—BEHAVIOR MANAGEMENT AT HOME OR IN THE NURSING HOME: Both behavioral management and the use of reality orientation help increase positive behaviors of the person with AD.

In both the patient's home and in the nursing home, the environment can play a major role in managing behavior.[6] Guidelines: 1) avoid environmental changes, 2) maintain a routine, 3) provide social stimulation, 4) structure time in small amounts, 5) use the person's long-term memory and 6) keep the patient's possessions nearby.[7] Environmental management can help behaviors based on habit and long-term learning remain intact longer.

Communication with the AD patient is important and requires a special brand of patience. "Communication provides a sense of security to patients that they are not alone and that there are people who will listen."[8] Successful communication involves 1) breaking down complex requests into steps, 2) accompanying all nonverbal activity with the appropriate verbal direction, 3) repeating directions exactly, 4) speaking in a manner that implies that a reply is expected, 5) avoiding complex messages and 6) dealing with the patient's rambling by gently returning conversation to the present by a direct question or a reminder. Since the AD patient has difficulty with verbal communication, touch (jiggling the hand, resting one's hand on the shoulder) can help focus attention.

The problem of a wandering patient is worrisome. One can walk up beside him/her, catch the person's attention and gently return him/her to the room. If the patient wanders at night, one might tie a loose-fitting strap between the patient and caregiver, who will awaken if the patient gets up.

Reality orientation[9] is a set of techniques designed to help persons with memory loss, confusion and time/place/person disorientation. It connects the person to the flow of time as well as to ongoing events and activities. The backbone of reality orientation is repetition and relearning of basic information such as name, place, time of day, week, month, next meal, next holiday, etc.[10, 11, 7] Reality orientation includes maintenance of a routine and a calm environment, orientation information in daily conversations and employment of a message board to post information such as day and year. Personal possessions also help keep the patient oriented. Suspicious reactions may be dealt with matter-of-factly; challenge and arguments should be avoided.

SESSION IV—FAMILY COMMUNICATION PATTERNS: AD represents a family crisis of catastrophic proportions. Each family reacts with its own unique pattern dependent upon several variables, including how this particular family has mastered crises in the past, roles in the family, flexibility of members' roles in response to changing patterns of interaction and responsibility, and the members' style of communication.[12]

This discussion will concentrate on the varieties of family styles of communication[13] as related to AD patients. Some families are open and the members feel comfortable talking about whatever they consider important. Some are less open and members have difficulty discussing specific topics—there are certain issues that everyone agrees, albeit tacitly, are not to be discussed. In other families communication is closed—few issues that engender conflict are confronted.

For families of AD patients, how will open or closed communication styles affect the family's response to the crisis? In an open family, members are able to communicate freely with each other and feelings are expressed spontaneously. Anxiety and feelings of loss may be alleviated through discussion. Members can make special requests regarding care and support and are able to interchange responsibilities and handle practical matters. However, open discussions can be painful and unpredictable—talking about feelings does not always resolve differences. Openness may also increase anxiety because issues are not ignored or denied. The long-term nature of AD often leads to increased potential for conflict since family members at different stages of the grieving process may perceive things differently.

Other families present a second level of communication called "mutual pretense awareness"[13] in which "everyone knows what is going on, but nobody is talking." These families tend to avoid painful discussions and conflict. While this may seem to be a positive outcome, these families experience the situation as disconcerting. Practical matters remain unsolved and visits to the patient are often avoided. Family members feel isolated and extra energy is required to maintain the pretense, particularly when the AD patient denies the problem.

The family with closed communication acts "as if" the individual with AD is not going to die and the patient is usually not informed of the diagnosis. Few, if any, visits are made to the patient, and the increased stress from the denial and dishonesty saps personal energy. Individuals in these families are less likely to resolve the grieving process. The patient is bound to be suspicious and distrustful in earlier stages of the illness. This level of communication also puts a strain on individuals outside the family who may disagree with the family decisions or who are afraid they may say something "wrong."

Understanding family communication patterns may help families of AD patients to label their own communication style and to change their level of openness in accordance with specific desired outcomes.

SESSION V—EMOTIONAL FACTORS: MANAGING THE GRIEF PROCESS: Once the diagnosis of AD is made and the disease begins to run its course, the patient and the family begin to deal with losses. Some are huge, like the loss of a spouse, and some are smaller and occur day-to-day, like the loss of the ability to dress oneself. Grief is the specific human reaction to losses.

Once a loss is incurred, people may begin the process of recovery. Grief work is a broad term which encompasses the confronting, working through, managing, coming to terms with, growing through, acknowledging and making peace with a loss. This grief work involves shuffling emotional investments, letting go, and reinvesting in new relationships.

The grieving process for the family with an AD patient is somewhat different than for a family who loses a relative to a sudden death. The patient with AD may not be gone physically but the person known emotionally to the family is gone -a symbolic death has occurred. The family finds it difficult to deal with the relative either at home or in the nursing home because it is as if a stranger is inhabiting their relative's body. When the relative ceases to be aware of who he/she is, a frequent occurrence, many family members find it helpful to think of their relative as dead in order to deal with pressing matters.

At this painful time increased demands are made on the family. These demands can include nursing home placement, financial losses, restriction of social contacts and loss of support. In addition, there are changes in accustomed family roles and a shift in emotional investments. As a result, family members often have to deal with increased emotional and financial responsibilities, loneliness, identity problems, embarrassment, guilt, helplessness, anger over the loss of control and other mixed and confused feelings.

As the inevitability of their relative's death become apparent, anticipatory grief work may begin; the family attempts to resolve the loss ahead of time in order to prepare for the death. When death occurs, this process changes to grief. The chance of returning to full functioning and having a shorter post-death grief experience is better for those individuals who experience anticipatory grief than for those who do not.[14]

The stages of grief are not set—they can overlap and recycle.[15] The first stage is one of shock, disbelief and denial. It can last from a few hours to a few weeks. A person may say, "No, it cannot happen to us." Somatic complaints include numbness, feelings of unreality, excessive talking and hyper- or hypo-activity. People may demand more tests, switch doctors or try to get a different diagnosis/prognosis.

The second stage is the anger, impact or protest period. It may last from one week to three months. Verbalizations may include, "Why us

and not somebody else?" Somatic manifestations may include fatigue, nausea, loss of appetite, body pain and sleep difficulties. During this period, when people feel angry, irritable and cheated, they may be critical of the patient, other family members and nursing home staff. The elicited anger and rage may be helpful in mobilizing the strength to face death.

Bargaining, the next stage, may last from three to six months. In desperation, a person may say, "If my spouse/father/mother will get well, I'll do anything!" While feeling sad, lonely, apathetic and isolated, decreased resistance to illness and restlessness are also common. People then move into a period of depression and disorganization which may last from three to six months. This hopeless time is characterized by lowered resistance to disease, light-headedness, nausea, sleep and eating difficulties. Aimlessness, confusion and disengagement may occur as the family focuses on memories.

The final stage is one of reorganization and acceptance. This period may last anywhere from six months to two years. A person may verbalize, "I feel both sadness and happiness, but I feel I can go on." Somatic functioning may return to normal. Pleasant memories of the relative tend to emerge and social functioning may be renewed. People frequently perceive that they have mastered the loss without bitterness or fear.

These categories are not separate in reality—everyone proceeds at his/her own pace. Recycling and regression are common.

Families frequently want to know what can be done to aid this process. Talking with friends and the relative can be helpful. Widening social networks to increase support and counteract loneliness are often recommended. Utilizing the available literature may prove helpful.[16, 17] Finally, it is most important for family members to care for themselves by getting enough rest, frequent medical checks and respite help.

SESSION VI—COMMUNITY AND NURSING HOME SUPPORTS: Obtaining adequate community resources at an affordable price is a major concern for the AD patient and family. Often the services are either unavailable or expensive, sapping the family emotionally and financially. Federal, state and local governments have largely ignored or been unable to provide adequate services.

A recent improvement in providing financial services in Colorado was Senate Bill 38, enacted January 1, 1981 by the Colorado General Assembly. The bill authorizes financial assistance for those people who are Medicaid eligible but still living at home. Previously, only those in nursing home care who were Medicaid eligible could receive the extra benefits. Also, the Colorado Department of Social Services has received a $100,000 grant from the Department of Health and Human Services aimed at determining the long-term care program most effective in avoiding institutional placement. This could be the beginning of increased funding for day-care, home-health care and similar programs which provide for the AD patient in his/her home.[18]

Insurance companies have been reluctant to pay for long-term care when constant medical supervision is not required. Therefore, funding is not available for the AD patient who can function with limited supervision during the early stages of the disease. If it could be demonstrated that treating the AD patient at home is less expensive than other care, coverage might be extended.

There are three legal strategies to manage, save or gain control of financial assets. First, and least troublesome, is obtaining a "power of attorney." Second, one can file for "conservatorship." Third, and usually painful, is filing for divorce.

When the AD patient shows deficits in intellectual and/or motor functioning and outside help is sought, placement in a senior citizen center or day-care center is appropriate. Unfortunately, most day-care centers are either too expensive or ill-equipped to manage the problems presented by the AD patient. Home-health care may be arranged at costs ranging from $6.50-$15.00/hour depending upon the caregiver. Since services vary widely, it is important to check quality of service.

Nursing homes also vary widely in cost and quality of service. It is important to research the nursing home for staff turnover, staff-to-patient ratio, daily activity schedules, medical care and consumer complaints.

RESULTS

All family members participating in the project were asked to complete a true-false questionnaire about AD, the Moos Family Environment Scale[3], and an Activities of Daily Living (ADL)[4] questionnaire and Kahn Mental Status Exam[5] for the AD patient. All instruments were administered pre- and post-test.

The true-false test on AD consisted of 30 items concerning normal aging, physiological changes characteristic of AD and supportive treatment of AD. The items were compiled from a variety of pamphlets, articles and books concerning aging and AD. Scores ranged from 23 to 29 out of 30 items on the pre-test and 23 to 30 items on the post-test, with means of 26.5 and 26.7 respectively. No significant difference was found between the pre- and post-test measures.

The Moos Family Environment Scale consists of items which determine changes in family environment as perceived by the spouse and other family members. The only scale to reach a significant level ($p = .05$) for pre- and post-test was the "independence scale," defined as "the extent to which family members are encouraged to be assertive, self-sufficient, to make their own decisions and to think things out for themselves" (p. 4).

The ADL questionnaire consists of 15 items evaluating the patient's level of functioning, including ability to dress, eat with or without help, do housework, etc. Although not significant, results found that relatives reported the AD patient to be functioning at a higher level after participation in the program.

The Kahn Mental Status Exam consists of 10 questions evaluating the AD patient's orientation to person, place and time. No significant difference was found from pre- to post-test.

In addition to the pre-post measures administered, participants were asked to rate how well various goals of the program were understood and their overall level of satisfaction. Educational aspects of the program were generally found to be either very well or completely understood. The small support groups were also rated as helpful. Informal comments concerning the direction of the program emphasized the usefulness of general psychological information; participants did not appear to benefit as much from educational information regarding the disease.

DISCUSSION

This pilot study was conducted with relatives of AD patients to determine whether their needs for support and information could be met through MFPSGT. Analysis of the data can be divided into two parts. First, did change occur in the AD patients during the 8 week period between evaluations and, second, did changes occur in the cognitive, emotional and behavioral states of the relatives who attended the sessions?

Results from the Kahn Mental Status Exam and the ADL questionnaire showed, as expected, that no statistically significant changes occurred in the patients. The time period was short and many patients were in nursing homes, functioning poorly, prior to the start of the sessions. There was, however, a trend on the ADL for group members to report a slight increase in the overall functioning of their relatives, even though skill levels were not perceived as changed. Several hypotheses may account for this phenomenon. Initially, group members may have evaluated their relative harshly due to high levels of stress and anxiety. As tension decreased through the educational/support sessions, members' perceptions may have changed or become more accurate. Another possibility is that the patient demonstrated actual improvement. It is possible that the group members' cognitive, emotional and behavioral changes were translated into better management and care, which resulted in slight functional improvement. Since the instruments used may not be sufficiently sensitive to measure change over a short period of time, the slight change reported may also be a reflection of retest rather than the result of any real change.

Some changes did occur in the relatives who attended the group sessions. The "independence" category on the Moos Family Environment Scale shows a statistically significant pre- to post-test change. This reflects the goal of helping family members recognize and fulfill their own needs in order to better care for the patient. In addition to informational components, both the lectures and small groups were designed to help family members recognize personal needs and the importance of attending to them. For many members this was a shift from constant vigilance and care-taking to permission to take care of themselves. Some significant family members were not present. We wonder whether the change in family members who did attend effected changes in other family members and, thus, in the entire care-taking network.

There was little change in knowledge of AD as tapped by the true-false questionnaire. Most participants had attended previous lectures and the high scores obtained reflected their knowledge. However, the summary evaluation indicted that participants did learn from information given and also from the general discussions that followed each presentation. Lectures identified as most helpful

were those that dealt with normal aging, biological aspects, family problems and grief work. Group members reported learning somewhat less from the behavioral management and community resources lectures. They may have been well informed about the limited number of behavioral tools available or not directly in charge of patient care. Community resource information generated much discussion, most of it frustrated and discourged in both content and tone. The lecture seemed to add to participant recognition of societal neglect and to their despair.

In general, the small groups were evaluated as helpful. Project staff and the recorders noted the increased sharing, support and modeling that occurred within each group. Group members who had placed their relative or spouse in a nursing home helped those contemplating the move. The opportunity to describe hardships and vent pent-up frustration was a source of great relief. The realization that others had similar experiences served as a reservoir of strength for coping. The focus on mutual problem-solving helped group members plot strategies to help themselves and the patient cope more effectively. Further demonstration of the effectiveness of the groups was shown by participant disinterest in follow-up or continued intervention. Instead, they formed their own outside support groups.

In conclusion, combining education and psychotherapy in a family support group setting (MFPSGT) is an effective treatment mode to deal with the anger, anxiety and guilt that arise once AD is diagnosed. Further research is indicted to support the utility of the model. We recommend a pre-post test to measure how family member's emotions, such as anxiety, depression and anger, may change as a result of the group process. It would be useful to have a control group and to measure effects over time, following family members to the relative's death and during the mourning period.

As public awareness of AD increases, requests for help by families will increase. MFPSGT holds promise as an effective and efficient way to intervene with these families.

May 20, 1982

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